A Guide for UK-Based Research Ethics Committees Assessing Health and Care Research with People with Impaired Capacity

Introduction

This guide is designed to support RECs in England and Wales to evaluate research proposals involving people with impaired capacity. It provides areas for REC members to consider when ethically and legally reviewing research proposals involving individuals with limited mental capacity. It offers practical advice to ensure research practices uphold ethical standards when working with individuals and groups who face communication and / or cognitive challenges to ensure ethical and inclusive research practices.

The concept of mental capacity can perhaps best be defined as **a person being able to make informed decisions about their life and wellbeing**. Someone with mental capacity has the ability to understand information (with varying levels of complexity) and its implications, remember it long enough to make decisions based on their understanding and consideration of that information, and then communicate their decision to others verbally through their preferred mode, including spoken and written words, sign language, pictorial symbols or computer-aided devices.

In research, people are deemed to lack capacity if, at the time a decision needs to be made that impacts their health or wellbeing, they are unable to: understand, retain or use/weigh up the information relevant to the decision-making process, and to effectively communicate their decision to others because of an impairment of, or a disturbance in the functioning of, the mind or brain **(Mental Capacity Act 2005)**.

Who Can Lack Capacity?

People's capacity can be temporarily impaired, for example if someone is intoxicated, under anaesthesia or unconscious. However, the main groups of people who are likely to have significant or long-term conditions which may affect their 'mental capacity' and ability to give consent to participate in research, or receive treatment include, but are not limited to, individuals:

- **At the end of their life**
- **People with long term conditions affecting cognitive functioning** (e.g. dementia or aphasia after stroke)
- **Individuals with Learning Disabilities**
- Or who have **Neurodevelopmental Conditions** (e.g., autism)
- People with **Acquired Brain Injuries**
- or certain **Mental Health Conditions** (including trauma-related conditions)

Other factors such as sensory impairments, communication difficulties or age-related frailty may also cause capacity to fluctuate and should be considered.

Adults with impaired capacity are under-represented in research due to concerns around gaining consent, methodological challenges and structural barriers to their participation. Evidence suggests that researchers may be put off from including or undertaking research with people lacking mental capacity due to its more resource intensive nature and Research Ethics Committees' (RECs) scrutiny around these issues (Shepherd, Hood and Wood, 2022). RECs need to scrutinise and justify the ethical basis for the inclusion of people with impaired mental capacity in research can appear as reluctance to include them. However, the prevalence of people with capacity-affecting conditions is increasing (Bunning et al., 2022). In 2013 The Care Quality Commission estimated that **2 million people** in England and Wales had significantly impaired decision-making, due to either acute medical events (e.g., stroke, or accidents resulting in acquired brain injuries) or long-term health conditions such as dementia and mental illness, or associated with learning disabilities, or at the end of life. (Shepherd, Hood and Wood, 2022). Thus, the exclusion of people with impaired capacity from health and social care research is particularly concerning in those health conditions where the prevalence of cognitive impairments is high (Shepherd et. al., op. cit,) and where less is known about what works most effectively to improve care (Shepherd, 2020). Accordingly, there is a lack of an evidence base for many interventions and treatments provided to people with learning disabilities, dementia and other areas of research including psycho-geriatrics, rehabilitation interventions, perioperative medicine, trauma and some types of neurological research (Shepherd, 2020).

Research which includes meaningful participation of people with such conditions can help to address inequities but does require special ethical protections to be embedded into such studies. However, the system of legal and ethical regulation is complex. In England and Wales there are two separate regulatory regimes governing research involving adults who lack capacity:

- **Clinical Trials of investigational medicinal products (CTIMPS)** are regulated by the Medicines for Human Use (Clinical Trials) Regulations 2004
- **Mental Capacity Act 2005** governs how adults lacking capacity can be involved in 'intrusive' research (see text box for definition)

There are significant differences between these regulatory frameworks, including the level of risk permitted, who acts as proxy decision maker, how much information is provided to the person lacking capacity, and whether or not the person lacking capacity retains the power of veto (Shepherd, 2020). This guide is aimed primarily at research governed by the MCA.

‘Intrusive Research’ Definition

The Mental Capacity Act (2005) defines intrusive research as research that would be considered unlawful if it were carried out on a person who had the capacity to consent without their consent. To determine whether a study is considered intrusive REC members should ask:

- **Have they used the Decision-making tool - Do I need NHS Ethics approval?**
- **What does participation involve and what are the risks involved for the person lacking capacity?**
- **Could the research question be answered without the involvement of the person lacking capacity?**
- **Will the information provided by a care giver or other informant about the person(s) who lack capacity significantly affect them in any way? E.g. asking about the participant’s dietary habits, or ability to undertake tasks, or accept medications etc.**
- **Is consent required from the person lacking capacity in order to process their personal data and administer questionnaires, undertake interviews or observations?**

Undertaking intrusive research involving people lacking capacity is **unlawful** unless it has been approved by the appropriate body, which would be a specialist ‘Mental Capacity Act Flagged’ Research Ethics Committee (hereafter MCA-flagged REC). All NHS Research Ethics Committees (RECs) established under the Governance Arrangements for Research Ethics Committees (GAfREC) are appropriate bodies for approving research (including research outside of the NHS) under the MCA 2005. Whilst it is technically possible for University RECs to become recognised, none has ever applied (Parker, Penhale and Stanley, 2011) and a recent check showed this still to be true.

The MCA (2005) and its associated **Code of Practice** were introduced explicitly to safeguard the rights of people who are unable to make decisions for themselves. Consequently, assessing research proposals involving people with impaired capacity by **MCA-flagged RECs** demands knowledge of the MCA (2005) and how to apply it in practice. However, the Code of Practice is widely considered to be out-of-date, and revisions proposed in 2022 are still under discussion. Thus, the guide can assist in providing clarity to non-CTIMPs which are governed by the MCA whilst updates are awaited. Further the key considerations below are applicable to all RECs as they promote an understanding of the diverse and complex needs of the groups that may have limited or lack capacity and how studies can be made more cognitively accessible.

Key Considerations for RECs Evaluating Research involving People with Impaired Capacity

One: Prioritise a Person-Centred and Flexible Approach

Person-centredness involves taking active steps to understand people's everyday experiences and create an environment that promotes 'personhood' – acknowledging and respecting their autonomy and dignity (Griffiths et al., 2022). Researchers must demonstrate a nuanced approach in their research with the individuals and group(s) under investigation, and their consultees, to ensure their meaningful inclusion. The REC members should consider whether the research proposal takes into account the individual contexts and settings experienced by potential participants and offers reasonable adjustments and supports. For example, does the proposal offer the opportunity to utilise person centred adaptations such as using communication tools, consistency of engagement with researchers (to reduce anxiety), working around care routines and using observational methods to gauge capacity (Griffiths et al., 2022)? RECs also need to recognise the resource intensive nature of these adaptations and ensure that appropriate timelines and funding are available to the research team to support high quality research.

Two: Prioritise Accessible Communication

It is absolutely crucial that consent procedures are designed to be as clear, unbiased and accessible as possible for both participants and other consultees, such as their carers (Griffiths et al., 2022). Reducing the cognitive load of documentation is extremely important to increase accessibility. Lengthy Patient Information Sheets (PIS) that cover all required information should be supplemented with a shortened PIS. All information should be provided in advance of any procedure or discussion, as is routine, with participants being given the opportunity to reflect on the content and raise any questions with the researchers. The information sheets and consent forms should be in formats participants can understand (e.g. translated into relevant community languages, designed to be 'easy-read', 'aphasia-friendly', 'dementia friendly', or using pictorial images, and permit the taking of verbal, witnessed consent where appropriate). REC panel members should consider whether information materials and consent forms were designed in collaboration with people with relevant lived experience such as individuals living with a particular condition and/or their carers or specialists from support agencies.

Lack of accessibility is an ethical flaw, not simply a procedural gap for researchers or a REC to overcome. The REC panel should look for evidence that the researchers have explored effective strategies to promote meaningful inclusion that move beyond participant information documents and support other mechanisms and contexts for information sharing and empowered decision-making. For example, the researchers should seek advice from those who know the person best, and use person-centred communication skills such as sitting face-to-face or side-to-side dependent on the individual's needs, building in time for supported conversations, presenting one idea or question at a time, allowing increased processing time to ensure that the participant with impaired capacity has understood a conversation, routinely incorporating repetition of information into dialogue with participants, and documenting the acceptability of audio or video recording consent gained from participants. (Bunning et al., 2022; Griffiths et al., 2022).

Three: Safeguard Autonomy and Dignity

Participants lacking capacity still have the right to express preferences, including disagreement with procedures or concepts which are proposed. The MCA encourages support for decision-making under its research provisions even where there is an in-built reliance on another person, (the consultee/carer), to advise the researchers on the likely wishes and feelings of the individual regarding their participation in a study. To support participant autonomy, it is essential that the REC panel explore how study designs have sought to maximise meaningful participant involvement in decision-making (Bunning et al., 2022). For example, have resources such as the Consent Support Tool (Bunning et al., 2022) been explored? Or how assisted technology might help facilitate decision-making? Has time been allowed for detailed, fully documented conversations to underpin the decision-making process (Bunning et al., 2022). Panel members should also explore researchers' level of knowledge, experience and strategies for judging both consent and objections or dissent (using both verbal and nonverbal cues) of participants, for example through awareness of facial expressions, disengagement or distress, including how such understanding can be supported by interpretation through a care giver or consultee.

Assisted technology can support people's decision making

Four: Assess Capacity and Consent Pathways Thoroughly

Whilst the starting assumption of the MCA (2005) is that people have capacity, panel members should look for **detailed plans** on how capacity will be assessed, if required, and how consent, or consultee advice will be obtained and recorded. It is important to explore who will be involved in assessing potential participants' capacity, and how well the described process meets the requirements of MCA legal test of capacity. Is the researcher trained in capacity evaluation or a healthcare professional with expertise? How would any disagreements between researchers and carers or medical staff, with regard to people's level of capacity be resolved. What processes will be followed if a participant's capacity fluctuates during the course of the research? The research team should also clearly demonstrate that they have adequately considered the advantages and disadvantages of the approaches they propose.

The MCA (2005) specifies that **capacity is decision specific and time specific.** The panel should take care to ensure that researchers assess participants' capacities within their specific setting (Griffiths et al., 2022) and that safeguards and requirements for checking on-going consent are built in. For example, the location where the consent process is carried out (if quiet, or in a busy location) can impact the participant's ability to fully understand what they are being told and is therefore crucial to their capacity to give consent. The time of day may also be relevant if someone is exhausted and potentially more confused by the evening or routinely requires a rest in the afternoon. Capacity fluctuations due to **changing health status** must be considered, and researchers should adopt a 'staged consent' approach, revisiting consent periodically using accessible formats suited to participants' needs and context. Temporary impacts on capacity can arise from conditions like infections, sedation, dehydration, depression, or anxiety, while progressive illnesses like dementia may cause ongoing or permanent loss of capacity. Staged consent affirms ongoing willingness, supports autonomy amid fluctuating capacity, and enables supported decision-making. This is especially important in longitudinal studies where initial consent may not ensure ethical participation. REC panels should assess if the consent model includes feasible, sensitive, and inclusive mechanisms for staged or repeated consent.

Five: Weigh Risks with Extra Care

When reviewing proposals which are either focused on or include participants with impaired capacity, REC members should scrutinise the **risk-benefit balance** extremely closely to ensure that participants are not at risk of being deprived of dignity or other fundamental rights, or could be induced to agree to decisions against their own interests without realising the full implications (Gilbert et al., 2017). This is especially important where participants may not fully understand what is required or expected of them, or may not be able to articulate distress.

It is crucial to recognise that the idea that decisions are being undertaken in the **'best interests'** of people with impaired capacity does not apply in a research context. Rather consultees are being asked to apply a substituted judgement approach.

Instead, RECs need to weigh the rights of the individual participant who lacks capacity against the value of supporting their inclusion in research and the wider future benefits to under-served populations (Bunning et al., 2022). The MCA (2005) states that the rights of the individual always take priority. Accordingly adequate safeguards, monitoring of the administration of research procedures, and appropriate withdrawal procedures are essential to ethical research with people with impaired capacity.

Six: Evaluate Research Team Knowledge

When drawing conclusions on the appropriateness of the research design, the REC should also reflect upon the level of experience of the research team in undertaking capacity assessments and conducting research involving people with impaired capacity. Researchers should demonstrate a thorough knowledge of the individual categories of people (and communities involved), particularly how to communicate effectively with people given the complex interplay between health conditions, level of capacity, and communication abilities and how intersectional issues may impact upon them (See point 7).

It is crucial that researchers should evidence understanding of the legal framework governing research with involving people with impaired capacity. RECs should therefore ask themselves the following questions: Does the proposal demonstrate appropriate depth of understanding of the ethical and legal issues involved? For example, does the project set out arrangements to identify a 'consultee' (see text box for definition) if a potential participant's capacity is in question? Will the research identify a sufficiently close and trusted relationship between the potential participant and their consultee which gives confidence in the validity of the research team's decision to accept such advice on the participant's likely wishes? Does the proposal clearly evidence how researchers plan to identify and include all parties in the research process? Does it set out reasonable arrangements on how it will deal with people who lose capacity during the project?

The REC panel should look for the use of appropriate terminology and definitions in the proposal, for example avoiding terms such as 'suffering' from a learning disability or a terminal illness, which may diminish the dignity and sense of agency and autonomy of a person.

Definition of "Consultee"

According to the MCA (2005), if it has been established that a person lacks capacity to agree to participate, then before they can be included in research, the researcher must consult with specified people to determine whether they should be included. In order to act as a personal consultee, that person (the consultee) must be involved in the person's care, interested in their welfare and must be willing to help. They must not be a professional or paid care worker or be connected to the project. They will probably be a family member but could be another person. They do not necessarily have to be someone who has legal responsibility for the person lacking capacity, such as a family member with Lasting Power of Attorney (LPA) or deputyship. They could be, for example, a sibling or grandchild who provides care and support on a regular basis. Where there is no-one who meets these conditions, the researcher must either nominate a professional or paid carer to be consulted or exclude the individual. This person does not need to belong to a specific profession, but they must not be connected to the project.
MCA Code of Practice 2007

Seven: Consider Intersectional Issues

Impaired capacity may intersect with a range of other issues such as people whose main language is other than English, or prior trauma: for example, they have experienced or are experiencing poor quality of care, or if someone has been hospitalised against their wishes with mental health challenges or arising through traumatic experiences during migration or asylum seeking. Ethical reviews must consider how multiple factors could compound circumstances that may give rise to vulnerability - and ensure protections are layered accordingly and reassessed regularly by the research team. For example, does the proposal include stated strategies for handling revelations of historic or current experiences of abuse or misconduct? Equally the research team should be alert to the concerns and issues which impact on people with impaired capacity and those who care for and about them. They need to consider that a person's intersectional characteristics such as their gender, age, ethnicity, sexual orientation, faith or belief and varying types of disability may be more important to them than their capacity issues. For example, someone who is gay and who has learning disabilities may be in a loving and close personal relationship with a partner that may not necessarily be understood or recognised by their legal guardians if they find the idea of such a person having any intimate relationship, let alone a same-sex relationship, challenging or concerning.

Eight: Providing Justification for Inclusion

According to the MCA (2005) researchers must provide clear justifications for including people with impaired capacity in their research. For example, even where research isn't specific to the population lacking capacity, reasons can include the investigation of a setting, issue or health condition where the prevalence of cognitive impairments amongst participants is high or where less is known about what works most effectively to improve care amongst people who lack capacity (Shepherd, 2020).

Scenario of poor practice and what the REC could have done better.

Scenario 1: A research proposal was submitted to an MCA-approved REC investigating how health professional communication and interaction with adults with learning disabilities (and their carers where appropriate) during Annual Health Checks supports their active participation and involvement in the review process. The subject covered by the proposal were all forms of communication and the sources of data to be investigated included any written documentation associated with Annual Health Checks and any interaction that takes place between the health professional and the individual. The proposal planned to analyse the presentation and language content of all documentation to check its level of accessibility. The researchers planned to capture the 3-way interactions that took place during the review using a camcorder for later analysis.

The REC's response:
The REC questioned the use of video in the project to record interactions and whether it was strictly necessary on the grounds that it was an 'insecure' method of storing data and impossible to anonymise. They returned the proposal to the research team recommending that audio recording be used to capture the health check interactions instead.

What the REC could have done better:

The REC should have questioned the research team about their choice of data collection method, asking why video recording was the preferred data capture method and more appropriate than audio-recording. They should have also sought further clarification about the modes of communication utilised by the target population, as speech is only one form of communication and if video is not considered to be a valid means of capturing data then it excludes a large swathe of people with non-verbal speech forms of communication from research including people with learning disabilities, BSL users with hearing loss, people with neurodevelopmental conditions such as autism and people with an acquired language disorder following brain injury or due to health conditions such as dementia, aphasia following stroke, and motor neurone disease.

They should have asked the research team how they could ensure the security of the information and protection of participants identities, exploring what protocols they had in place such as the use of an encrypted SD card and then uploading the footage to a secure storage location.

Scenario of poor practice and what the REC could have done better.

Scenario 2: A university-based research team proposed a longitudinal arts-based study exploring the role of creative engagement in supporting wellbeing and memory among older adults living with early-stage dementia. The project involved a series of weekly group sessions over six months in which participants co-produced visual and narrative artworks reflecting on their lived experiences of ageing. The intention was to understand how participatory arts activities affect social connection and identity among people with cognitive impairment. Participants were to be recruited via community dementia support groups. Participants' verbal reflections were to be audio-recorded and their artworks photographed. Some written prompts would be used to guide discussion. The research team proposed obtaining informed consent at the start of the project, with carers serving as consultees for those with borderline or fluctuating capacity. However, the project did not include detailed guidance on how to manage situations where participants lost capacity part-way through the study.

The REC's response:
The REC expressed concern about including participants who might lose capacity during the study, questioning whether they could continue in the research and suggesting their data might need to be withdrawn if consent could no longer be reaffirmed. The REC also noted that while carers were included in early-stage discussions, there was no plan for ongoing consultation or participant re-engagement around consent.

What the REC could have done better:

The REC should have recognised that under the Mental Capacity Act (2005), participants can continue in research after losing capacity if safeguards are in place. Rather than questioning continued participation, the REC could have asked the team to clarify how they would manage capacity changes, such as documenting ongoing willingness, appointing a nominated consultee if needed, and monitoring for signs of distress or dissent.

In participatory, relationship-based studies (e.g., arts-based dementia research), ending participation solely due to capacity loss can harm wellbeing, disrupt established relationships, and affect identity. The REC could have encouraged safeguarding approaches that reflect these ethical nuances, rather than focusing only on reconsent.

They also missed the chance to ask about dementia-inclusive communication strategies, like visual tools, creative prompts, and simplified reminders, which support engagement when verbal abilities decline.

Finally, instead of viewing fluctuating capacity as a barrier, the REC could have promoted inclusive consent pathways supported decision-making through carers, revisiting consent accessibly, or using tools like pictorial cards or recorded preferences. Ethical research requires flexibility, creativity, and a commitment to sustaining participants' voices, which the REC could have better supported.

Checklist for RECs

Involvement and Co-production

- Were people with relevant lived experience meaningfully involved in study design?
- Does the research team utilise a person-centred approach, exploring and offering reasonable adjustments to enable inclusion?
- Does the study offer participants with impaired capacity opportunities to express their preferences and make decisions?
- Were information and consent materials designed in collaboration with people with relevant lived experience?

Understanding the Population

- Does the research team demonstrate understanding of the range of people with impaired capacity?
- Are other issues (sensory and communication difficulties, age-related vulnerabilities) considered?
- Are intersectional issues considered?

Managing Practical Issues

- Does the research have appropriate timelines and funding in place to enable inclusion?
- How will capacity be assessed?
- How will consent and/or consultee advice be obtained and recorded?
- Is accessibility (capacity, communication, health status, timing) adequately addressed?

Safeguarding and Trauma

- Are consent and withdrawal processes on-going (not one-off)?
- Are the risks to the potential participant with impaired capacity greater than the benefit of the research to the wider population?
- Are trauma-informed approaches embedded throughout the research design?
- Are researchers trained in managing distress and safeguarding issues?
- Are clear referral pathways for participant support outlined?
- Are vicarious trauma risks for researchers acknowledged with support plans?

Further Reading and Resources

Mental Capacity Act 2005

Mental Capacity Act - Code of Practice

Mental Capacity Act - Health Research Authority

Ethics Review Form for Mental Capacity Act (MCA) Studies (Lead Reviewer/REC Member) - Health Research Authority

Decision-making and mental capacity - NICE guidance 2018

Research Inclusion Guidance:

Assent Guidance – including adults who may lack capacity and may have communication difficulties in ethically sound research

ACCORD - Addressing consent-based challenges to improve inclusivity in research
Communication guidance and resources:

Communication Guidance - Mental Capacity Toolkit

Accessible Communications Policy - RNID

Communicating with people with a learning disability | Mencap

Communication and capacity - Capacity consent research

Accessible Information Guidelines -making information accessible for people with aphasia - Stroke Association_.pdf

Accessible Writing Guide for People with Dementia

Easy Read | Foundation for People with Learning Disabilities

Easy Read Services - Opening Doors

Bibliography

Bishop, R., Laugharne, R., Shaw, N., Russell, A.M., Goodley, D., Banerjee, S., Clack, E. and Shankar, R. (2024) 'The inclusion of adults with intellectual disabilities in health research – challenges, barriers and opportunities: a mixed-method study among stakeholders in England', Journal of intellectual disability research, 68(2), pp. 140–149 Available at: https://doi.org/10.1111/jir.13097.

Bunning, K., Jimoh, O.F., Heywood, R., Killett, A., Ryan, H., Shiggins, C. and Langdon, P.E. (2022) 'How are adults with capacity-affecting conditions and associated communication difficulties included in ethically sound research? A documentary-based survey of ethical review and recruitment processes under the research provisions of the Mental Capacity Act (2005) for England and Wales', BMJ open, 12(3), pp. e059036 Available at: https://doi.org/10.1136/bmjopen-2021-059036.

Gilbert, T., Bosquet, A., Thomas-Anterion, C., Bonnefoy, M. and Le Saux, O. (2017) 'Assessing capacity to consent for research in cognitively impaired older patients', Clinical interventions in aging, 12, pp. 1553–1563 Available at: https://doi.org/10.2147/CIA.S141905.

Griffiths, S., Gude, A., Greene, L., Weston, L., Sutcliffe, C.L., Wheat, H., Oh, T.M. and Byng, R. (2022) ''Do I have the capacity to make capacity judgements?' Researcher reflections from a person-centred dementia support study', Dementia (London, England), 21(3), pp. 972–994 Available at: https://doi.org/10.1177/14713012211067320.

Harrison, R.R. (2024) 'The ethical inadequacy of uninformed surrogate consent: advancing respect for persons in clinical research', Theoretical medicine and bioethics, 45(6), pp. 461–479 Available at: https://doi.org/10.1007/s11017-024-09693-z.

Kim, S.Y.H., Uhlmann, R.A., Appelbaum, P.S., Knopman, D.S., Kim, H.M., Damschroder, L., Beattie, E., Struble, L. and De Vries, R. (2010) 'Deliberative assessment of surrogate consent in dementia research', Alzheimer's & dementia, 6(4), pp. 342–350 Available at: https://doi.org/10.1016/j.jalz.2009.06.001.

Parker, J., Penhale, B. and Stanley, D. (2011) 'Research Ethics Review: Social Care and Social Science Research and the Mental Capacity Act 2005', Ethics and social welfare, 5(4), pp. 380–400 Available at: https://doi.org/10.1080/17496535.2011.594448.

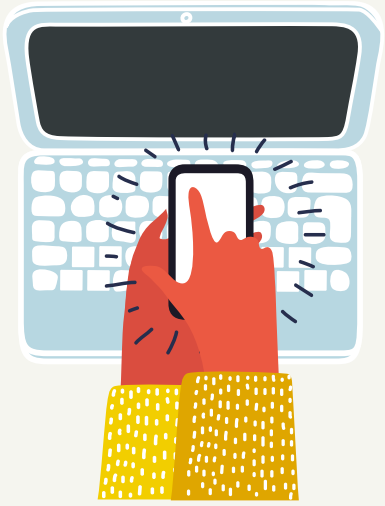
Shepherd, V. (2020) 'An under-represented and underserved population in trials: Methodological, structural, and systemic barriers to the inclusion of adults lacking capacity to consent', Current controlled trials in cardiovascular medicine, 21(1), pp. 445 Available at: https://doi.org/10.1186/s13063-020-04406-y.

Shepherd, V., Hood, K. and Wood, F. (2022) 'Unpacking the 'black box of horrendousness': a qualitative exploration of the barriers and facilitators to conducting trials involving adults lacking capacity to consent', Current controlled trials in cardiovascular medicine, 23(1), pp. 471 Available at: https://doi.org/10.1186/s13063-022-06422-6.

Willner, P. (2018) 'The UK Mental Capacity Act and consent to research participation: asking the right question', Journal of medical ethics, 44(1), pp. 44–46 Available at: https://doi.org/10.1136/medethics-2016-103996.

Wood, F., Prout, H., Bayer, A., Duncan, D., Nuttall, J., Hood, K. and Butler, C.C. (2013) 'Consent, including advanced consent, of older adults to research in care homes: A qualitative study of stakeholders' views in South Wales', Trials, 14(1), pp. 247 Available at: https://doi.org/10.1186/1745-6215-14-247.

KEEP IN TOUCH



This factsheet was written and designed by **Catherine Kennelly, Sophie Coker** and **Margaret Greenfields** from **Anglia Ruskin University.** This report was commissioned by the **Research Office of NHS Cambridgeshire and Peterborough Integrated Care Board**, with funding from the **Department of Health and Social Care / NHS England Research Engagement Network** development programme for integrated care systems.

Email: margaret.greenfields@aru.ac.uk
Website: https://www.peoplepoweredresearch.org

Many thanks to our critical readers for their knowledge and expertise:

- Dr Caroline Barry, Consultant - Palliative Care, Norfolk and Norwich University Hospitals Foundation Trust
- Dr Victoria Shepherd, Principal Research Fellow, School of Medicine, University of Cardiff
- Prof Karen Bunning, School of Health Sciences, University of East Anglia
- Prof Rob Heywood, School of Law, University of East Anglia
- Dr Martyn Patel, Consultant - Older People's Medicine, Norfolk and Norwich University Hospitals Foundation Trust
- Prof Ryan Woolrych, Director of the Urban Institute, Ageing and Urban Studies, Heriot-Watt University, Edinburgh

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